Disability Awareness Month

VOLUNTEERISM AS ADVOCACY

During Disability Awareness Month each March, Indiana disability advocates organize hundreds of activities to promote the statewide awareness campaign's theme and message. Activities include awareness fairs, essay contests, library displays, mayoral proclamations and more. Another way to affect attitudes about disability is to organize people with disabilities to do volunteer work in their communities. These activities will cause people to reexamine their assumptions and stereotypes about people with disabilities, and hopefully help them appreciate the *abilities* of people with disabilities.

A spirit of volunteerism is as valuable for people with disabilities as it is for the community as a whole. Studies show that 70 percent of people with disabilities who are of working age are unemployed. These people often can and want to work, and volunteering is a great opportunity to gain valuable work experience – honing skills no classroom can teach. Volunteers might be able to learn a skill that translates into paid employment, as well as meet people who might serve as references for a job. In addition, volunteering helps increase independence and self-confidence and provides immediate emotional satisfaction.

Volunteering makes sense as a form of advocacy. As people with and without disabilities volunteer alongside one another, or as volunteer coordinators work with a group of people with disabilities, the people without disabilities will reconsider their assumptions and stereotypes

about people with disabilities. They will observe first-hand that people with disabilities have many *abilities* and usually require only minor accommodation, if any, to complete tasks. As they get to know people with disabilities personally, people without disabilities will begin to understand the "people first" concept – that people with disabilities are, first and foremost, people.

The news media – newspapers, radio stations and television stations – are a key audience for your volunteer efforts. The news media have the power to spread your advocacy message to a larger group of people than you would be able to reach personally. Coverage of your volunteer-driven events, and of Disability Awareness Month, will have a positive impact on people's attitudes about disability. Journalists are accustomed to covering events in which people volunteer on behalf of people with disabilities. They might be intrigued by an event powered by people with disabilities.

Planning

The first step in planning is a meeting with members of your group who plan to volunteer. Explain the benefits of volunteering and how this will be an advocacy effort. Then ask about their preferences. Where and how would they like to volunteer? Where do they feel their skills and efforts would be most needed and/or appreciated? Volunteers will be more effective when they are enthusiastic about their cause, so be sure to consider their suggestions as you plan the event. It is also a good idea to establish several potential volunteer days that fit most group members' schedules. This way, you can schedule volunteer efforts without having to wait for the next group meeting to confirm a date.

Working with a local nonprofit organization

Many nonprofit organizations are in constant need of volunteers. They probably will be thrilled to work with your group to arrange a project that spreads the message of Disability Awareness Month. Contact local nonprofit organizations you feel could use your services. Suggestions include:

- The American Red Cross
- Homeless shelters
- The Salvation Army
- Soup kitchens
- Habitat for Humanity
- Animal shelters
- Women's/children's shelters
- Community beautification programs
- After-school/youth programs

Depending on your group's preferences, also consider working with an organization within a local high school. Most high schools have many groups that volunteer, such as student government organizations, service organizations, language clubs, honor societies and more. Ask to speak with the faculty sponsor of such an organization. The sponsor will be able to tell you what projects the group is planning and how your group could participate.

Once you have chosen the organization with which you would like to work, call and ask to speak with the volunteer coordinator. Offer suggestions about how your group of people with disabilities could contribute time to the organization, and ask about the organization's needs.

Your group's abilities and the organization's needs won't always be compatible, but if they are, choose a date in March that works for everyone.

On the appointed day, make sure you and your group arrive on time, ready to work.

Punctuality will translate into a smooth beginning for the project of the day. It is important to make a good first impression because this could be the first step in a relationship that will help people with disabilities gain skills, independence and self-confidence.

When your project is complete, consider sending a thank you note to the volunteer coordinator. Show your appreciation of his/her willingness to work with your group and make everyone feel at ease. If the project went well, mention that you would be willing to work with the organization again and would like information on how to help in the future. If possible, allow all the members of your group who volunteered to sign the card.

Developing your own project

Instead of working with an established community organization, you might want to develop your own volunteer project to take place during March. Try to think of a project people would not expect people with disabilities to tackle, and tailor the project to your abilities or the abilities of the people in your group. Also, consider the needs in your community. You will impact more community members if your group is part of the solution to a significant community problem.

Some suggestions include:

1. Weather permitting, organize a "wheel-a-thon," "hop-a-thon," "walk-a-thon," etc. in your town to raise money for a local nonprofit organization. Use your imagination for what kind of "thon" you hold – make it appropriate for your message to include all types of participation from people with and without disabilities. Ask participants to collect

sponsorships and donations to be given to an organization you have specified. Lay out a course and provide prizes to the winners. You might also consider producing T-shirts to sell to participants and spectators.

- 2. Arrange for members of your group who have visual disabilities and read Braille to conduct Braille story hours with children at a library or in an after-school program or elementary school classroom in March. Choose several popular children's books from which the children can select, or choose a book dealing specifically with disability. Allow time at the end of the story hour for children to ask questions. (An alternative is group members with visual disabilities volunteering as readers to senior citizens.)
- 3. Select a community organization your group would like to support financially (see the list in the above section for suggestions). As a group, hold fund raisers for your selected organization during March. Suggestions include:
 - Bake sale. Group members will have a great time preparing baked goods as a group. With permission, you can sell your goods at a store, such as Wal-Mart or Target or outside a grocery store or a worship service.
 - Car wash. Weather permitting, members of your group can run a donations-only car wash in a busy area.
 - Raffle. Ask several local businesses to donate prizes. Sell raffle tickets to friends, family, congregations, community members and others.

When you have completed your fund raising, write a check (minus your expenses) to the organization you have chosen. Make sure all group members know the amount of your donation, and don't forget to notify the news media about the group's efforts.

- 4. Group members who have completed some higher education might consider serving as tutors at the elementary or secondary school level. For fun, and to make the tutors more recognizable to students and the media, consider giving the group of tutors a name. Contact guidance counselors at local schools to find out what their needs are; for example, some might be in need of English tutors, while others might need science tutors more. Arrange tutoring appointments through the counselors. (As an alternative, start an adult literacy program in your community, meeting at local libraries or community centers.)
- 5. Organize a neighborhood watch program for your community, if it does not already have one. Plan a community meeting in March to address needs and organize the effort, and include people with disabilities in every aspect of the planning and presentation to the community. Emphasize the Disability Awareness Month 2002 theme: "Together, we can reach new heights." Tell the community that, working together, we can all feel more secure.
- 6. Using donations from local congregations, hotels and stores, assemble kits for distribution in March to homeless shelters. Include toiletries, such as shampoo/conditioner, soap, toothbrush/toothpaste, deodorant, facial tissue, Band-Aids, a small brush and safety razors.
 Depending upon the donations you can obtain, consider including washcloths, gloves, sewing kits, small first aid kits, food items (such as granola bars or dried fruit) and a list of organizations that offer assistance to the homeless. Ask your local shelter for other suggestions of items for inclusion.
- 7. Sponsor a clothing or canned food drive in March to benefit shelters or other organizations in your area. Group members might be able to stage a musical or dramatic performance, or a speaking engagement, for which admission could be canned goods or a bag of clothing. If a group member with a disability has had unique experiences or overcome significant barriers,

ask him/her to consider speaking. (As an alternative, group members could staff tables in high-traffic areas in the community, such as grocery and discount stores, to request and accept donations.)

- 8. Organize a community beautification event or program. Consider cleaning up a community area, such as a park or school playground. Or, with the permission of the appropriate authorities, plant shrubs, flowers and other plants to beautify these areas: Consider working with a local greenhouse or gardening supply store on this project. For a long-term effort, enroll in the "Adopt a Highway" program. (For more information, contact your regional Indiana Department of Transportation office.) In Indianapolis, consider enrolling in the "Adopt a Median" program by calling (317) 327-2991 (voice).
- 9. Take "orders" from people who would like their address numbers spray painted on the curb in front of their houses for a donation to a specific cause. (Check with your local government to confirm that this is permissible and what style/colors should be used.) Gather a group together on a weekend to travel to these houses to paint the numbers and collect a donation (\$5, \$10, etc.).

Working with the media

Your message – that people with disabilities are capable of completing just about any activity – will reach the greatest number of people through the news media. Before your volunteer activity, issue a media advisory that answers basic questions such as who, what, where, when, why and how. Also include any other information you think is important. After the event is over, send a news release explaining the results of your efforts. Tell how many volunteer hours were donated or how much money was raised. Remind the media that the volunteer service is in conjunction with Disability Awareness Month.

Examples of a media advisory and news release are included at the end of this packet.

Adapt them to your needs, and send them to reporters or assignment editors at local newspapers, television stations and radio stations. Check the media outlets' Web sites or the phone book for contact information. When you receive coverage, it is appropriate to send a thank you letter.

Sometimes a reporter with the best intentions uses language in a story that creates negative impressions of people with disabilities. Examples include "the handicapped" or "the disabled person." If you receive such media coverage, send a thank you letter, but also include suggestions and a set of guidelines for correct language when referring to people with disabilities. A sample letter is enclosed, along with "Guidelines for Reporting and Writing about People with Disabilities," produced by the Indiana Governor's Planning Council for People with Disabilities.

Extending your efforts

If your first volunteer experience goes well, consider volunteering year-round. Develop a partnership with a local nonprofit organization that needs volunteer services on a regular basis.

Or, continue the efforts you created as a group.

The more and longer people with disabilities volunteer, the more they will realize the positive results. People with disabilities who volunteer on a regular basis have a greater opportunity to learn marketable skills, become more confident and independent, and develop relationships that could lead to future references or recommendations for a job. In addition, the act of volunteering is emotionally rewarding and life-affirming.

Realize, however, that volunteer coordinators might need more information before feeling comfortable about establishing a long-term relationship with your group. Be prepared to explain and answer questions about ADA requirements for accommodations, for example.

Remind coordinators that most accommodations require little or no financial investment. Also, provide coordinators with a copy of *Interacting with People with Disabilities*. This will answer coordinators' (and other volunteers') questions about what to say and how to interact with people with disabilities. To order *Interacting with People with Disabilities*, call Kim Dennison at (317) 631-6400 (voice).

(Sample Media Advisory)

For Immediate Release Contact:
(Date) (Your name)
(Your phone)

(People with Disabilities Support Group) members to volunteer in conjunction with awareness campaign

What Members of the (People with Disabilities Support Group) will

partner with the (Anytown Community Organization) to

(landscape a local community park, making it more welcoming and

relaxing for all community residents).

When (Monday, March __)

(10 a.m. to 5 p.m.)

Where (Anytown Community Park)

(1234 Main St.)

Why The (People with Disabilities Support Group) is volunteering as

part of Disability Awareness Month, an annual statewide awareness campaign sponsored each March by the Indiana Governor's Planning Council for People with Disabilities.

Who Members of the (People with Disabilities Support Group) and staff

members at (Anytown Community Organization).

Note (People with Disabilities Support Group) members and (Anytown

Community Organization) staff members will be available for interviews. For more information, call (Jane Doe) at (123-4567).

(Sample News Release)

For Immediate Release Contact:
(Date) (Your name)
(Your phone)

(Volunteers plant more than 500 flowers, shrubs at Anytown Community Park)

(Anytown), Ind. – Members of the (People with Disabilities Support Group) (planted more than 500 flowers and shrubs) on (Monday, March --) at (Anytown Community Park). The group partnered with (Anytown Community Organization) to make the park more welcoming and relaxing for all (Anytown) residents.

"We are thrilled to be able to contribute to improvements in our community," said (Jane Doe, president of the People with Disabilities Support Group). "People with disabilities have so much talent and skill to offer the community, and this event is just one example of this."

The (People with Disabilities Support Group) volunteered as part of Disability Awareness Month, an annual statewide awareness campaign sponsored each March by the Indiana Governor's Planning Council for People with Disabilities.

For more information about the (People with Disabilities Support Group) or other Disability Awareness Month activities, please contact (Jane Doe) at (123-4567).

(Sample Thank You Letter – With Suggestions for Appropriate Language)

(Date)

(Mr. John Doe) (Title) (XYZ Media) (123 Main Street) (Anytown, Indiana 46000)

Dear (Mr. Doe):

Thank you for your recent article/broadcast about our organization/event. Although we always appreciate coverage about people with disabilities and the issues that concern them, it is also important to realize that the way a reporter tells a story can make a significant difference in how people with disabilities are perceived in the community.

Reporting on the disability community is just like reporting on any other minority group; there are "correct" words and phrases to use. The Indiana Governor's Planning Council for People with Disabilities and other disability organizations emphasize "people first" language that focuses on the person first, with the disability as secondary. For example, woman who is deaf is preferred over deaf woman. In addition, people with disabilities is preferred over the handicapped or the disabled.

I have enclosed "Guidelines for Reporting and Writing about People with Disabilities." The guidelines explain preferred terminology when reporting about people with disabilities and reflect the input of more than 100 national disability organizations.

If you ever have a question these guidelines don't address, please feel free to contact me. Again, we appreciate your coverage of our organization and people with disabilities in general.

Sincerely,

(Your Name) (Title)

enclosure

Guidelines for Reporting and Writing About People with Disabilities

When writing, it's important to be concise, particularly in journalism. However, sometimes the effort to limit wordiness leads to inappropriate references to people with disabilities. The following guidelines explain preferred terminology and reflect input from more than 100 national disability organizations. These guidelines have been reviewed and endorsed by media and disability experts throughout the country. Although opinions may differ on some terms, the guidelines represent the current consensus among disability organizations. Portions of the guidelines have been adopted into the "Associated Press Stylebook," a basic reference for professional journalists.

DO NOT FOCUS ON DISABILITY unless it is crucial to a story. Avoid tear-jerking human interest stories about incurable diseases, congenital impairments or severe injury. Focus instead on issues that affect the quality of life for those individuals, such as accessible transportation, housing, affordable health care, employment opportunities and discrimination.

PUT PEOPLE FIRST, not their disability. Say "woman with arthritis," "children who are deaf" or "people with disabilities." This puts the focus on the individual, not the particular functional limitation. Despite editorial pressures to be succinct, it is never acceptable to use "crippled," "deformed," "suffers from," "victim of," "the retarded," "the deaf and dumb," etc.

DO NOT SENSATIONALIZE A DISABILITY by writing "afflicted with," "crippled with," "suffers from," "victim of" and so on. Instead, write "person who has multiple sclerosis" or "man who had polio."

DO NOT USE GENERIC LABELS for disability groups, such as "the retarded" or "the deaf." Emphasize people, not labels. Say "people with mental retardation" or "people who are deaf."

EMPHASIZE ABILITIES, not limitations. For example:

- Correct: "uses a wheelchair/braces" or "walks with crutches"
- Incorrect: "confined to a wheelchair," "wheelchair-bound" or "crippled" Similarly, do not use emotional descriptors such as "unfortunate," "pitiful" and similar phrases.

Disability groups also strongly object to using euphemisms to describe disabilities. Terms such as "handi-capable," "mentally different," "physically inconvenienced" and "physically challenged" are considered condescending. They reinforce the idea that disabilities cannot be dealt with directly and candidly.

SHOW PEOPLE WITH DISABILITIES AS ACTIVE participants in society. Portraying persons with disabilities interacting with people without disabilities in social and work environments helps break down barriers and open lines of communications.

DO NOT PORTRAY SUCCESSFUL PEOPLE WITH DISABILITIES AS SUPERHUMAN. Many people with disabilities do not want to be "hero-ized." Like many people without disabilities, they wish to be fully included in our communities and do not want to be judged based on unreasonable expectations.

DO NOT IMPLY DISEASE when discussing disabilities that result from a prior disease episode. People who had polio and experienced after-effects have a post-polio disability. They are not currently experiencing the disease. Do not imply disease with people whose disability has resulted from anatomical or physiological damage (e.g., person with spina bifida or cerebral palsy). Reference to the disease associated with a disability is acceptable only with chronic diseases, such as arthritis, Parkinson's disease or multiple sclerosis. People with disabilities should never be referred to as "patients" or "cases" unless their relationship with their doctor is under discussion.

LISTED BELOW ARE PREFERRED WORDS THAT REFLECT A POSITIVE ATTITUDE IN PORTRAYING DISABILITIES:

- Brain injury. Describes a condition where there is long-term or temporary disruption in brain function resulting from injury to the brain. Difficulties with cognitive, physical, emotional or social functioning may occur. Use "person with a brain injury," "woman who has sustained brain injury" or "boy with an acquired brain injury."
- *Cleft lip*. Describes a specific congenital disability involving lip and gum. The term "hare lip" is anatomically incorrect and stigmatizing. Use "person who has a cleft lip" or "a cleft palate."
- Deaf. Deafness refers to a profound degree of hearing loss that prevents understanding speech though the ear. "Hearing impaired" and "hearing loss" are generic terms used by some individuals to indicate any degree of hearing loss from mild to profound. These terms include people who are hard of hearing and deaf. However, some individuals completely disfavor the term "hearing impaired." Others prefer to use "deaf" or "hard of hearing." "Hard of hearing" refers to a mild to moderate hearing loss that may or may not be corrected with amplification. Use "woman who is deaf," "boy who is hard of hearing," "individuals with hearing losses" and "people who are deaf or hard of hearing."
- Disability. General term used for a functional limitation that interferes with a person's ability to, for example, walk, lift, hear or learn. It may refer to a physical, sensory or mental condition. Use as a descriptive noun or adjective, such as "person living with AIDS," "woman who is blind" or "man with a disability." "Impairment" refers to loss or abnormality of an organ or body mechanism, which may result in a disability.
- *Disfigurement*. Refers to physical changes caused by burn, trauma, disease or congenital problems.

- *Down syndrome*. Describes a chromosome disorder that usually causes a delay in physical, intellectual and language development. Usually results in mental retardation. "Mongol" or "mongoloid" are unacceptable.
- Handicap. Not a synonym for disability. Describes a condition or barrier imposed by society, the environment or by one's self. Some individuals prefer "inaccessible" or "not accessible" to describe social and environmental barriers. "Handicap" can be used when citing laws and situations, but should not be used to describe a disability. Do not refer to people with disabilities as "the handicapped" or "handicapped people." Say "the building is not accessible for a wheelchair-user." "The stairs are a handicap for her."
- *HIV/AIDS*. Acquired immunodeficiency syndrome is an infectious disease resulting in the loss of the body's immune system to ward off infections. The disease is caused by the human immunodeficiency virus (HIV). A positive test for HIV can occur without symptoms of the illnesses, which usually develop up to 10 years later, including tuberculosis, recurring pneumonia, cancer, recurrent vaginal yeast infections, intestinal ailments, chronic weakness and fever and profound weight loss. Preferred: "people living with HIV," "people with AIDS" or "living with AIDS."
- *Mental disability*. The Federal Rehabilitation Act (Section 504) lists four categories under mental disability: "psychiatric disability," "retardation," "learning disability" or "cognitive impairment" is acceptable.
- *Nondisabled*. Appropriate term for people without disabilities. "Normal," "ablebodied," "healthy" or "whole" are inappropriate.
- Seizure. Describes an involuntary muscular contraction, a brief impairment or loss of consciousness, etc., resulting from a neurological condition such as epilepsy or from an acquired brain injury. Rather than "epileptic," say "girl with epilepsy" or "boy with a seizure disorder." The term "convulsion" should be used only for seizures involving contraction of the entire body.
- *Spastic*. Describes a muscle with sudden abnormal and involuntary spasm. Not appropriate for describing someone with cerebral palsy or a neurological disorder. Muscles, not people, are spastic.
- *Stroke*. Caused by interruption of blood to brain. Hemiplegia (paralysis on one side) may result. "Stroke survivor" is preferred over "stroke victim."

The Indiana Governor's Planning Council for People with Disabilities would like to acknowledge the Research and Training Center on Independent Living at the University of Kansas for the usage rights of the "Guidelines."